

Finding and Hiring Helpful Support Staff

By John Mayer

Charley is a 25-year-old young man with SMS who is supported with a community-based program in his town of Portsmouth, NH. This article is written by his father and offers personal suggestions for ways to find staff able to work with an SMS adult.

When young adults with SMS age-out of the school system, their parents (or guardians) face new challenges created by a new and less-structured environment. Developing a plan for adult life, building a successful program of activities, finding supports, even securing social services, involve associations with many new people, agencies, and governmental systems.

Beginning a process early to address these issues, well before graduating, can be critical in forming alliances and in establishing a successful process for transition to adult and perhaps community life. Needless to say, there are many factors to be considered involving resources available, the family's capacity to support the program, and knowing what works with the SMS adult. Taken all together, the choices to be considered and decisions to be made can be overwhelming.

And for those who are looking to develop activities in the community, unless they intend to provide the needed support themselves, hiring staff to deliver and manage the program will be critical for success.

What do you want?

As you begin this process of program planning, establishing a vision and focus for your efforts is critical.

Ask yourself and any other members of your support team questions like, "What

is possible?" "What is the right thing to do?" "Is it sustainable?" "What happens when we are no longer able to help?" The answer to these and many other questions will lead you in the planning process. It truly is a process and should involve at least an annual review of the situation – so these questions will never go away.

As part of the process, being open to learning from others is healthy and important. Over the years, as we developed our plans for Charley, Debora and I participated in a leadership program sponsored by the New Hampshire Institute on Disabilities*, interacted with local family support groups, attended conferences and workshops, and talked with specialists, families and others. It seems unending – but more than anything, reaching for a possible future and being able to describe it is important.

(* similar Institutes on Disability exist in every state. Contact the Association of University Centers on Disability at www.aucd.org)

Charley's program is designed to reach for the greatest access to our community and to work with the least amount of restriction. We have been influenced by the concepts of community care and self-determination. Our experience has shown that he enjoys and thrives in situations where there are natural supports, and he can be part of the decision making process.

Currently, Charley is supported in a "community-based" program. He spends his days doing a variety of jobs for local businesses, running errands and completing chores that address his residential or daily-life needs, and enjoying social and recreational activities. The intent is that his day is meaningful to him, provides ways to be involved and

connected in his community, and establishes a structure for routine and behaviors necessary for independent life.

There is no center or workshop or other space that serves as a starting or ending place. His home, the businesses where he works, and the places in the community he enjoys provide a "natural" structure for him.

He is aided by a "staff" person, otherwise known as a "direct support professional" or "teacher" – as Charley calls them. To avoid burn-out, we divide the week between two people – one works with Charley two days, the other, three days of the week.

More than any other team member, his day-staff are crucial parts of his program and are vital for meeting program goals and developing long-term plans for Charley. Unfortunately, keeping these staff people has been difficult. Finding good helpers is a continuing challenge.

Here are some of the factors that make the staffing process difficult:

1. SMS is a difficult condition to support. Like others with SMS, Charley can be impulsive and aggressive, and his emotional needs are variable.
2. Working in the community means there is no central office. Staff needs to be able to vent, to share and get help. Building redundancy or being available for back up is important but challenging.
3. Providing training and orientation for new helpers takes a very long time. Keys to success includes orientation to SMS, behavior management and disability issues, as well as building a relationship with the person they will be supporting.
4. Finding candidates who are caring, interested in teamwork and respectful is

rare. Yet these qualities are critical and make for the best helpers.

Compensation. It is important to pay people well. We pay nearly twice the starting hourly rate offered to workers by local agencies.

Program Management. There are many models and strategies for care – the design and choices made will reflect the interest and capacity of parents or providers, and also may reflect the unique resources available in your community.

To support Charley, we have tried two different systems: 1) contracting with a “vendor agency” that hires, trains and supervises staff, and 2) managing the program as a family and making those hiring decisions ourselves.

The vendor agency model is appealing largely because there is a management structure in place to handle much of the hiring process (at least that is the concept). Often an agency will provide back-up support and perhaps even “seamless” coverage. But there is a cost to this – generally a range of expenses involving management, training and overhead which take away from the resources that could be used for programming.

In our experience, this ideal, where hiring and backup coverage is effectively provided, rarely has been achieved. Instead, we have waited months for replacement staff, been presented with unqualified and uninterested options, experience frequent turn-over, and been expected to provide the necessary orientation for new staff.

The bottom line has always been that stability and consistency is important. Change and turmoil is hard for Charley, and the associated chaos carries over into the home environment.

For many of these reasons, we are currently working with a family-managed approach. The greatest downside to this

scenario is that the responsibilities for all aspects of the program rest with the family. Not everyone is in a position to consider this type of program – the demands are significant. In our case, only one parent can work full-time. (The associated pressures with this can be the subject of another essay.) But the reality has been that many of the duties have always rested with us anyway.

Finding Help. When seeking staff, we have increasingly relied on Craigslist for posting notices. There are few other alternatives – newspaper classified ads are virtually obsolete. We also try to tap into our network of community resources and broadcasting our need through word of mouth. But more than any other resource, Craigslist has become a vital tool to post our announcements.

Before posting, it is important to be prepared for the responses in a couple of ways – have information ready to share about the position, including a job description and overview of the program. Also, be ready to manage the replies by keeping a log and a file with the e-mails and supporting information received from each applicant.

Standards for managing these inquiries are really different than traditional job applications. In this new “on-line” environment people do not follow through, they don’t show up for meetings, they fail to formally withdraw, and you are exposed to all kinds of inquiries, some not legitimate. Use caution for spam and viruses.

Compared to job searches of even ten years ago, there truly is a different standard for communicating. We try very hard to keep people informed and to be considerate and polite with our communications. This means extra work in keeping track of the status of the various applications. Unfortunately, more work is the last thing you need. But setting a standard of caring is appropriate and carries over in the way people work with you.



Interviews and Match-Making. When reviewing applications it is important to have a clear idea about the skills and qualifications you are seeking. An open-minded approach is good – you never know what will come your way – but you should have a firm idea of what qualities would make an ideal helper.

Finding a good match for Charley has never been easy. It is difficult to find people who accept the possibility of being hit. They also need to be able to see the benefit and importance of community involvement, they need to transcend his intense emotional moments with flexibility and humor, and they need to be caring and committed.

Once an application has been received, we review the applications and rank them in terms of appropriateness – good, possible, or not qualified. Any candidates who are not qualified are sent a note thanking them for their interest. Those candidates who are “possible” are placed in a holding pool. The “good” candidates are called on the phone.

For phone and in-person interviews, a standard list of questions further distinguish candidates and ensure important points have been covered. We ask questions like, “What are your experiences with disabilities?” “Why are you interested in this position?” “Have you worked in community settings?” “What are your greatest strengths and weaknesses?”

If the phone interview is positive, a direct interview is the next step and if others are involved in the program, they too should be part of the in-person meeting. These meetings often involve a repeat discussion

of your standard questions as well as the job description and program goals. But most importantly, they provide a time to interact with the candidate and to learn more about his/her personality.

And if all this seems to be going well, another meeting is set up so they can meet with Charley. Ultimately, his relationship with the helper is vital. A good relationship comes from mutual trust, respect and sincere enjoyment between one another. When this is in place the program works successfully and there can be stability and growth.

Including Charley in the interview can be very interesting – often we use the card game, UNO, as a way to create a social opportunity. And Charley will understand we are looking for someone to help him – so he can ask a few questions as well.

As a final step in the process, we set up times for candidates to shadow during the day so they can see the type of situation we have developed. This provides a chance to observe a potential staff person in on-the-job situations.

Closing the Deal. If all of these steps have worked well and a decision to hire a candidate has been made, there is a final

step in the selection process that includes a check of references and a background search. Our area agency will help with the background search that includes a check of driving and criminal record. Phone calls to references also involve a standard set of questions to ensure a complete and consistent understanding is developed.

Hopefully, these final steps will yield positive results, and you can move forward with hiring a great helper for your program.

Then the work begins to provide orientation, one-on-one training and creating opportunities to build a relationship with Charley. All of this will take time. The goal is to establish a successful routine and then fade from the daily program. Best not to rush any of this – ultimately, you want there to be a good and healthy relationship for the program to build upon and to last a long time.

Summary Thoughts

For families with a young adult with SMS and who are looking to develop a community-based program, finding help is a critical need. If they are taking on these duties themselves, the responsibility can be overwhelming. Developing a

thoughtful structure and establishing a plan to find staff will greatly assist in these efforts.

Our greatest dream is to have access to a pool of many qualified and capable helpers. But this is never the case. That said, with a deliberate and thorough process, we have been fortunate in finding dedicated and thoughtful helpers who have been involved in Charley's life.

Take courage and be positive. It can be done and it is possible to develop a meaningful and successful program that will provide support and growth.✿



This article is a reprint from Spectrum, the quarterly newsletter of PRISMS. PRISMS is the non-profit organization Parents and Researchers Interested in Smith-Magenis Syndrome. PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMS. Please visit www.prisms.org for more information or to make a donation.